

**REPORT TO THE TWENTY-FIRST LEGISLATURE
STATE OF HAWAII
2002**

**PURSUANT TO SECTION 321-291, HAWAII REVISED STATUTES
REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN
ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND**

**PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
DECEMBER 2001**

EXECUTIVE SUMMARY

The Hawaii Newborn Metabolic Screening Program (NBMSPP) is administered by the Hawaii State Department of Health. NBMSPP has statewide responsibilities for assuring that all infants born in the State of Hawaii are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases that are added to the screening panel. This program tracks and follows up on infants to assure satisfactory testing and to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment. The objectives are to prevent and ameliorate the effects of handicapping conditions that are identified through the administration of newborn screening and diagnostic testing.

In 1996, legislation was passed (Act 259), which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

The Hawaii Administrative Rules, Chapter 11-143, revised and adopted on June 19, 1997, reflect the following changes:

- Expansion of the newborn metabolic screening testing battery to include tests for:
 - Phenylketonuria (PKU)
 - Congenital Hypothyroidism
 - Galactosemia
 - Hemoglobinopathies
 - Congenital Adrenal Hyperplasia (CAH)
 - Maple Syrup Urine Disease (MSUD)
 - Biotinidase Deficiency
- The newborn screening fee of \$27.00 per specimen collection kit beginning July 1, 1997, includes:
 - Laboratory testing for the seven disorders;
 - Repeat testing for initial specimens collected at less than 24 hours of age;

- Confirmatory testing up to the point of diagnosis if specimens are sent to the designated testing laboratory;
 - Overnight mailing costs of the initial specimens to the testing laboratory;
 - Tracking of infants, continuing education, screening costs for the uninsured indigent; and the administration of the statewide newborn screening system.
- Responsibilities of a centralized newborn screening testing laboratory.

The attached financial report for FY 2001 (July 1, 2000 to June 30, 2001), required by § 321-291, HRS, identifies all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund and the purposes of each expenditure.

**Report on Non-General Fund Information
for Submittal to the 2002 Legislature**

DEPARTMENT: HEALTH

DATE:
PREPARED BY:
PHONE:

October 1, 2001
Calvin Kunihi
x6-4559

NAME OF FUND: Newborn Metabolic Screening Special Fund
LEGAL AUTHORITY: Section 321-291, HRS
FUND TYPE (MOF): B
APPROP ACCT NO: S 302 H

INTENDED PURPOSE:

This fund is to be used for payment of its lawful operating expenditures, including, but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

CURRENT PROGRAM ACTIVITIES:

The Newborn Metabolic Screening Program (NBMS) has statewide responsibilities for assuring that infants born in the State of Hawaii are satisfactorily tested for seven disorders which can cause mental and growth retardation and even death, if not detected and treated early in the newborn period. NBMS tracks and follows-up on infants to assure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities are quality assurance, continuing education, and standard setting.

Financial Data		
	FY 2001	FY 2002
Beginning Cash Balance	288,834.91	308,765.51
Beginning Encumbrances	94,420.72	66,145.62
Revenues	479,660.89	
Expenditures	430,658.58	
Transfers (List Each Transfer by JV# and Date)		
JV #JM2665 - 12/11/00	29,071.71	
Net Total Transfers	29,071.71	
Amount Derived from Bond Proceeds		
Ending Cash Balance	308,765.51	
Amount Required for Bond Covenants as of 7/1/01		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/01		

PURPOSES OF EACH EXPENDITURE FOR FY 2001

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 F.T.E.)	\$153,205.27
B.	Car mileage	410.09
II.	Implementation of newborn screening system utilizing a centralized laboratory:	
A.	FedEx courier services to deliver specimens overnight to the newborn screening testing laboratory	31,525.19
B.	Oregon State Public Health Laboratory for comprehensive newborn screening testing services	231,582.00
C.	Newborn screening testing for the indigent/uninsured	223.47
D.	Fax machine maintenance	458.64
E.	Toner cartridge for fax machine	178.88
F.	Computer repair	875.76
G.	Tyvek envelopes for the mailing of specimens to the centralized laboratory	1,136.70
H.	Fireproof Safe for data diskettes	328.15
I.	Stationary and office supplies	254.29
J.	Other miscellaneous	50.00
III.	Staff education	
A.	National Neonatal Screening and Genetics Testing Symposium, Raleigh, North Carolina	1,732.64
B.	Books on Low Protein Cookery for PKU and Low Protein Food List	149.85
IV.	Provider education on newborn screening	
A.	Neighbor Island newborn screening education sessions	528.24
B.	Dr. Berkeley Powell's CME sessions on Neighbor Islands	1,769.50

V.	Parent education on newborn screening	
A.	Thalassemia Action Group Patient/Parent Conference	722.50
VI.	Nutrition services for clients with metabolic disorders	<u>5,527.41</u>
	TOTAL	\$430,658.58

JV#JM2665: Assessments for central services and administrative expenses for FY 00	\$29,071.71
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BEGINNING ENCUMBRANCES FY 2002

Laboratory Services	\$25,707.62
FedEx Courier Services	1,231.14
Personnel	3,490.00
Car Mileage	399.24
Intra-State Travel Per Diem	10.00
SD Ram 64 DIMM	186.46
Fax Machine Maintenance	56.16
Annual Meeting of the Hawaii Society for Clinical Laboratory Scientists	65.00
Assessments for central services and administrative expenses for FY 2001	<u>35,000.00</u>
TOTAL	\$66,145.62